

Hope Eka.S.H.A.

A Voluntary Organization Dedicated To The Care Of Alzheimer's Disease Patients & Their Caregivers. Granted Special Consultative Status by United Nations ECOSOC







Annual Report 2019 - 20







Our Ongoing Projects Inside

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ABOUT Hope Ek A.S.H.A.

Hope Ek A.S.H.A. is a leading NGO in NCR Delhi that has been relentlessly working for past 19 years to provide respite to the family caregivers by providing respite to the patients with dementia and Alzheimer's and also creating awareness about Dementia / Alzheimer's disease. The organization came into being in 2001 and was founded by Dr Sushma Chawla, a medical practitioner based in New Delhi with a sole purpose of caring of Dementia patients and their caregiver thus imparting specialised knowledge to the families having Dementia patients.

While serving the society for so long with their skill based programmes to provide services for patients with dementia and help family caregivers to overcome all sorts of challenges associated with dementia care, the organisation also had a vision to set up an Alzheimer's Home where patients with dementia can be in admitted for medical and necessary nursing facilities round the clock under the supervision of medical professionals to improve the quality of their life as in India there are no specialised hospitals for Dementia Care.



This was made possible with the vital support of The Hans Foundation when Hope Ek ASHA opened its first Day care and specialised residential Skilled Nursing Care Facility in New Delhi to rehabilitate and reform the special class of senior community suffering from devastating Alzheimer's Disease in June 2019 under the brand ASHA – **"Affectionate Secured Home for Alzheimer's".** It is a first and only Dementia Care Facility in Northern region of India offering specialised Nursing situated in New Delhi formally inaugurated on 11th August 2019.

MISSION

To open more Skilled Nursing Centre like ASHA (Affectionate Secured Home for Alzheimer's), Residential and Day Care facilities for Alzheimer's Disease patients all around Northern Region based on the Pilot Project at New Delhi.

VISION

VISION

Our

Mission

Our mission is to establish a "DEMENTIA VILLAGE" for 100 Alzheimer disease patients gradually by involving healthy willing senior citizens / spouses.

CORE STRATEGY

To focus on formation of Alzheimer's Friendly Society.

SECTOR(s)

Sectors of Working – Memory issues, Its Management, Controlling and Counselling.



ACTIVITIES

- Providing medical care to the **Patients with Dementia (PwD)**
- Mass Awareness about Alzheimer Disease
- Home Care of patients and their caregivers.
- Memory Assessment.
- Training to Family and Professional Caregivers.
- Online Support to the caregivers.
- Hope At Home (Programme designed Specially during COVID-19)

OUR ONGOING PROJECTS DURING 2019-20

Affectionate Secured Home for Alzheimer's – A.S.H.A. (A Skilled Facility Centre for Day Care & Residential Care Patients) at New Delhi.

Memory Assessment for All above 50 Years - to identify the cases of MCI (Mild Cognitive Impairment) to advise the treatment and brain stimulation activities to considerably slow the memory decline at the right time.

Hope At Home - An Online Programme, an Initiative of Day Care Activities for **PwD** designed during COVID-19.

OUR FUTURE PROJECT - UNDER PROCESS

Mobile Medical Clinic cum Memory Screening Unit - Delayed due to COVID-19 and likely to take shape in the coming year.

INAUGURAL OF SKILLED NURSING CENTRE AFFECTIONATE SECURED HOME FOR ALZHEIMER'S (A.S.H.A.)

Affectionate Secured Home for Alzheimer's is a Skilled Nursing Centre for Day Care & Residential Care. It is a Facility for Alzheimer Disease Patients. Its formal opening was announced on 11.08.2019 by Dr. Emandi Sankara Rao, MD & CEO of IFCI Limited and Lt. Gen. S. M. Mehta (Retd), Chief Executive Officer of The Hans Foundation in the presence of our core team associated with the NGO Since 2001 along with other members, beneficiaries.



Dr. Sushma Chawla, President of NGO narrated its journey starting from its formal inception and played short clips of activities conducted at ASHA in the previous week.

Gen. Mehta while speaking expressed that The Hans Foundation normally funds in the areas of Education, Health, Mental disability, Agriculture. This is their first skilled Nursing Center funded on Alzheimer's in Delhi and he felt satisfied to see the Facility created by Hope Ek ASHA.

Dr. E. S. Rao congratulated to whole team of NGO and expressed his happiness that the Capital Funds supported by IFCI Social Foundation has been properly utilized at the facility.

Shri Talwant Singh Hon'ble Judge of Delhi High Court and Legal Head of our NGO conveyed his sincere thanks to The Hans Foundation and IFCI Social Foundation for the support extended to us. He also mentioned the courtesy extended by the landlord Shri H. K. L. Magu for giving his space to our NGO for opening this facility which normally people do not give.

Dr. Priya Jha, Chief Psychologist explained how her team is taking care of the patients at the facility. Shri S. C. Kalra who was the caregivers for his father nearly 12 years also shared his experiences of care giving while in association with Hope Ek ASHA. since 2001.

Memento was given by Shri Talwant Singh to Gen. Mehta and Dr. E.S. Rao. The event was attended by 35 participants.

Vote of thanks was extended to all dignitaries at dias and others by Dr. Sushma Chawla President of Hope Ek A.S.H.A.

The programme ended with National Anthem followed by working lunch. Few photographs of inauguration and the video of link is <u>https://youtu.be/hlgUzB0Tlb4</u>





ADMINISTRATION SET-UP AT THE CENTRE

Day Care & Residential Care centre has been provided the best of facilities narrated as under :

- Hostel facility for the medical and paramedical staff.
- Necessary Medical equipments.
- General and Medical Furniture.
- Provision of Oil Heaters to cope up with extreme weather conditions.
- Physiotherapy Equipments.
- Installation of Kangen Water production.
- Provision of the Air Purifiers in the facility
- Reclining Chairs for Patients



To view video of tour of ASHA click the link https://youtu.be/lrR-dEhA2Oo



FACILITIES AT CENTRE

Skilled Nursing Centre for day care and resident facility for dementia patients is equipped with all general and medical infrastructures. It is a comfortable, compassionate home for dementia patients where they are kept under the supervision of dedicated trained nurses, caregivers, coordinators medical professionals and therapists which offer specialised care to patients who are battling with this disease. It attempts to improve their quality of life and emotional well-being with a



disciplined and well-researched programme that involves brain-stimulating exercises, physiotherapy, especially designed activities and most importantly medical and personal care.

In its service of over a year, the centre has been able to really make a lot of difference in the lives of families and caregivers whose loved ones are with us as Day Care or Residential Care Patients.

A - Residential Care Facilities at the Centre

PwD are housed in the facility as family members under complete care of paramedical and medical professionals. Dedicated caregivers for the patients are their true companions. Behaviour patterns and medical condition of the patients are regularly monitored. Comfort and convenience of the patients are paramount at the centre. It has patiently-friendly rooms, accessories and well-equipped bathrooms with all safety gears for the ease of movement as per their requirements. In-house cooking ensures clean and hygienic food for the patients which also caters to their meal preferences as well.

Key Features

- 24-hour clinical and nursing staff
- 24-hour supervision and medical care
- Personalized care plans
- Physiotherapy Facility
- Wheel Chair Access
- Emergency response system with daily check-up
- Health and wellness monitoring





- Family and friend connection support
- Housekeeping and personal laundry
- Individual daily memory activities
- Rooms Fitted Air Conditioners & Heaters
- In-house Kitchen Facility
- > 24X7 Electricity & Water Supply
- CCTV System & Security
- Open Space for Stroll & Seating
- Robust calendar of social and recreational programs

B - Day Care Facilities at the Centre

The day-care service at centre is one of its kinds in the Northern India. It is a happy gathering of **PwD** who look forward to a day full of fun and activities, socialising with fellow patients and enjoying life to the fullest, oblivious of being burdened by a debilitating disease. Every day from Monday to Friday our centre welcomes its inbound patients who are escorted by their family members to the centre to spend their day under a specialised care team.

Key Features

- Well-structured Activities for Patients
- Well-Trained, Passionate & Uniformed Professionals
- Skill caregivers & trained nursing staff
- Friendly & Caring Environment
- In-house Kitchen Facility
- Open Space for Stroll & Seating
- CCTV System& Security

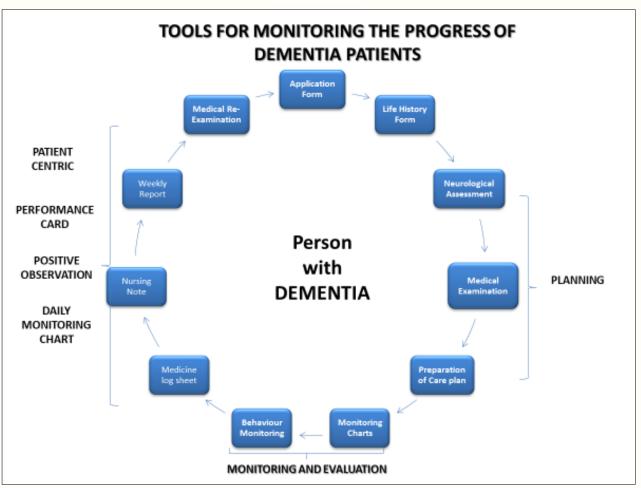












GUIDELINES FOR MONITORING AND EVALUATION OF PwD

- Measurements of Vitals
- Logging Nursing Notes Listing All Actions Eating, Bathing, Sleeping, Stool.
- Writing Behavior Notes (Morning & Evening) and its Management
- Check on Frequency of Urine / Stool
- Intake Medicines
- Follow-up Daily History Case Sheets
- Maintaining Diet Chart in Consultation with Dietician
- Management of behaviour
- Maintaining Activity Format
- Posture Management Like Seating, Lying Down with or without Air Bed.



MONITORING FORMATS FOR DEMENTIA PATIENTS

RESIDENTIAL CARE	DAY CARE
1. Daily Schedule of Dementia Patients	1. Daily day care activity sheet
2. Daily changing formats	2. Day care Roaster
3. Care plan for Dementia Patients	3. Activity monitoring sheet
4. Activity monitoring sheet	4. Weekly health Update
5. Daily health monitoring sheet	5. Assessment report card
6. Weekly health Update	6. Deliverable monitoring sheet
7. Assessment report card	7. Positive changes observed
8. Deliverable monitoring sheet	8. Recent Memory card
9. Positive changes observed	9. Daily Behaviour Management
10. Daily Behaviour Management	

ONLINE SUPPORT PROGRAMME FOR FAMILY CAREGIVER'S

Our NGO has a dedicated Global Online support system for the caregivers whose family members are suffering from Dementia. The Stress associated with care giving leads to caregivers' burnout leading to physical and mental health issues. The Online program aims to decrease their stress thereby improving the quality of life of those caring for people with Dementia.

Online support programme also caters to

- General information about Dementia
- Information related to being a carer.
- Self-Care.
- Care for the person with dementia
- Addressing changes in symptoms and behaviour of dementia patients.





PROGRESS NARRATIVE FOR THE YEAR 2019-20

As a part of our ongoing project, here are the details of achievements and activity implementation from April 2019 to March 2020.

Key Achievements

- 1. Drastic Increase in the number of day care patients.
- 2. Increase in number of residential care patients.
- 3. Increase in the number of queries to avail for the residential facility. On record presently we have 80 enquires coming in.
- 4. Increase in the number of patients coming for neurological assessment.
- 5. First time introduction of B-Neurofit programme at the facility : In order to focus on their cognitive concerns related to memory, thinking and communication, a very special B Neurofit programme was conducted by a clinical psychologist Ms. Banika Ahuja for the day care and residential care patients for eight weeks.

Post completion of this programme, showed amazing results in improving cognitive abilities of the patients as the programme also focused cognitive stimulation and training for individuals suffering from Dementia across different stages.

- 6. **Training for Caregivers :** A formal training was conducted by Epoch Elder Care at the centre for our caregivers on the skills to handle dementia patients. The training was led by Ms. Neha Sinha, CEO, Epoch Elder Care and Ms. Prasitha, Clinical Facility Manager, Epoch Elder Care.
- 7. **In-house Trainings :** In-house trainings for the overall growth of the caregivers in the following areas :-
- Personality grooming
- Challenges faced by caregivers
- Use of new activities for the patients
- Communication & Safety
- Techniques for patient management
- Techniques to enhance self confidence
- Understanding techniques for management of AD patients



- **CPR Training:** CPR is the most important life skill necessary to learn for everyone in this fast moving world so that one is able to help someone in saving his / her life An in-house CPR training session was conducted by Dr. Chawla and Dr J. Kailash for the caregivers, nurses and the entire staff of facility.
- 8. Hiring and replacement of staff.
- 9. **Celebration of festivals and Birthdays :** Celebrations is an important activity of centre to make everyone feel important. We celebrate birthdays of all the residential / day care patients and the staff members at A.S.H.A
- 10. **Meals :** Meals are an important part of the facility. Each menu is designed keepin in mind the nutritional value of the food. A detailed intake is taken about the likes and dislikes of the patients before designing the menu for them. Special arrangements for food are made on occasions like the birthday's and festivals for them to get connected to their past memory which enhances the cognitive skills of the patients. Though meal timings are common for all the patients, however they can be altered on case to case basis. We serve breakfast, lunch, dinner and snacks to all the patients in the facility.

HEALTH CARE OPERATIONS FOR PwD

Four Categories

- **1. Physical Activities**
- 2. Social Activities
- 3. Cognitive Activities
- 4. Music Activities

Purposes of Activities

- > To make them as independent in life as possible.
- > To help them keep in touch with the world around them.
- > To improve their daily functional ability.
- > Maintaining their dignity thus bringing improvement in the quality of their life.



1. PHYSICAL ACTIVITIES

Improves

- Mental Health
- Moods
- Thinking Process
- Learning Skills
- Maintaining Healthy Body Weight.
- Reduces Risk of Various Illnesses.

Types

- Sittercises (sitting exercise for all)
- Standing Exercises (for physically active clients)
- Pranayam (Simple breathing exercises like BhramariPranayam and Anulomvilomi)
- Laughter Therapy
- Playing with light balloons / balls
- Clapping together with Rhymes and Movements

Upper Body / Lower Body Sittercises

- Neck exercises
- Facial exercises
- Posture care
- Shoulder mobility
- Chair aerobics
- Brain gym
- Heart strengthening exercises
- Patting for blood circulation
- Strengthening of hands and wrist

All exercises counting are done till 10 for each step to make activities simple.

- Knee exercises
- Foot exercises
- Hip joints strengthening
- Restless legs relaxation
- Walking
- Upper body stretching



A Glimpse of Physical Activities by Pwd



2. SOCIAL ACTIVITIES

Purpose

Social environment has a great deal of impact on the development of Neurodegenerative disorders. Maintaining a high level of social activity not only decreases stress but also improves mood and delay the damaging effects of the disease.

Types

- Having meals together
- Visit to a park (in summers)
- Celebrations in house Festivals
- Reading story books
- Doing fireless cooking together

- Baby therapy
- Birthdays celebrations
- Playing bingo, cards
- Group singing
- Passing the parcel game
- Watching TV (old films, songs, actors and actresses)
- Playing games together like Carrom / Ludo, name impulse, tamboline.
- White board games like word / number games, comprehension practice, story building



A Glimpse of Social Activities by Pwd



3. COGNITIVE ACTIVITIES

Purpose

Regular structured cognitive retraining helps in slowing down of cognitive impairment in people with Dementia related to:-

- 1. Attention span
- 2. Thinking pattern
- 3. Their social communication
- 4. Sensory and motor skills
- 5. Behaviour patterns / mood swings
- 6. Co-ordination like eye and hand co-ordination Bilateral co-ordination
- 7. Depressive symptoms reduce

A. Reminiscence Therapy

It is used to maintain good mental health of people with Dementia. It is a process of recalling past experiences, events and memories like.



- 1. Folding laundry
- 2. Separating coriander and mint leaves
- 3. Shelling peas
- 4. Looking through photo albums
- 5. Baby Therapy
- 6. Fireless Cooking

B. Memory Games

Memory games help in improving recent memory.

Types

- Word puzzles
- Word gamesI spy games
- Left hand writing
- Number puzzles
- Card games
- Back counting
- Memory tray Game

C. Sensory and Motor Skill Activities

These activities stimulates all senses, supports actions of muscle, promoting coordination alertness and concentration.

Types

- Music therapy
- Hand and foot massage
- Folding handkerchiefs
- Following patterns
- Thread / Vegetable / cotton painting
- Tearing and pasting
- Writing with non-dominant hand
- Playing instruments
- Puzzles / blocks
- Art and craft activities

- Colouring
- Cake cutting
- Watering plants
- Buttoning
- Matching / sorting things
- Playing instruments
- Playing instruments
- Stringing of beads / wool work
- Art and craft activities
- Throwing and catching and walking (large muscles involved)



A Glimpse of Cognitive Activities by Pwd with Facility Team



4. MUSICAL ACTIVITIES

Purpose

People with Dementia generally feel calmed, encouraged and uplifted by prayers.

Types

- Songs and hymns are played from their era for their spiritual well-being.
- Singing in groups.
- Reading stories / short passages from books.
- Watching music programmes on T.V.
- Celebrating Festival



Celebrating festivals

Observations

- Sleep patterns have shown a lot of improvement.
- Reciting songs and hymns are very soothing for brain and they all participate happily.
- Singing together has strengthened their voice and a lot of positive changes have been observed on the health of their throats.

MAIN CHALLENGES IN IMPLEMENTATION OF THE PROJECT

Over the last one year there have been a lot of challenges related to the project but we at A.S.H.A. have been able to sail through it and have tried to provide the bests of services to our elders who are suffering from this disease.

The challenges came from all angles such as families, caregivers, medical challenges and finally handling **PwD** by caregivers on individual basis.







LESSON LEARNT

Learning has been an ongoing process while working at ASHA. It has taught us many teachings in the past a year which has really helped us to enhance our operations.

Some of them are follows:

 Training of the Staff : Training of the new staff in the field of Dementia is an important aspect of ASHA. So, before we assign a patient to a particular caregiver, he / she is mentored under a mentor for one month and then a patient is assigned to that particular caregiver. The most important learning in dementia management that no matter how much you train the staff for handling these patients still a lot of on the hands on training is carried out while handling the patients.

Like for e.g. communication, use of sign language when a patient is not receptive, handling their abusive languages and aggression which if not handled can be fatal for the caregiver. Thus, this gave another format to ASHA which was called the Behavior log sheets where the behavior of the patients is logged in to assess their behavior pattern.

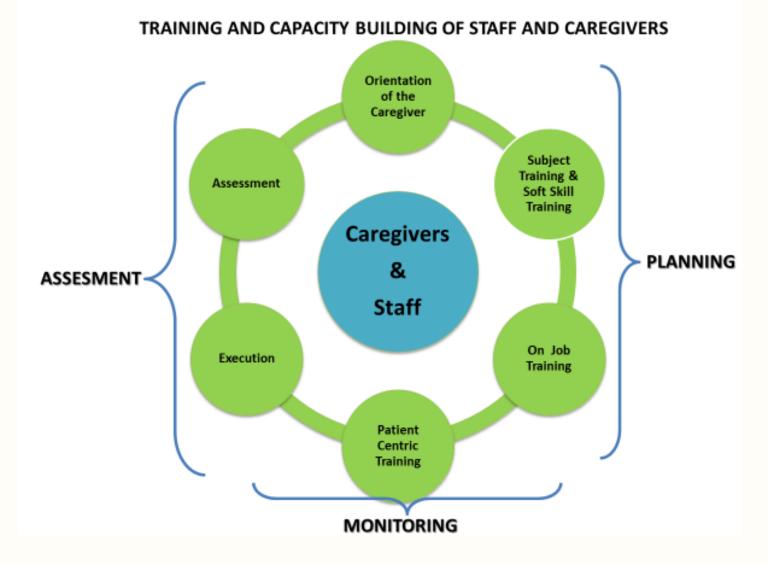
2. **Preventing Caregivers burnout:** While caring for the AD patients, the caregiver may experience some burn out. ASHA takes utmost care in managing this challenge. One to one counseling sessions are conducted with the caregivers to assist them in things they are dealing with.

Like for example due to this pandemic since all the caregivers were shifted in the hostel, all the three meals are provided to them. We had to start the celebration of birthdays of all the staff at ASHA as they were not able to go to their families for a long time. This has given them a sense of belongingness with the organization.

- 3. **Progression of the disease for patients in stage II:** As the disease progresses there is a progression of the disease, so the objective at ASHA is to slowdown the progress by rigorously adhering to the regimen crafted for care giving.
- 4. Handling Anxiety of the patient's relatives: Apart from handling the patients one aspect of care is handling the anxiety of the patient's family which is quite challenging. We have designed slots where the family members can come and interact with Project Head and senior administrative staff of the facility to allay any fears or stress they may have for their loved ones.
- 5. **Need for a Bigger Space:** With growing number of day care patients and residential patients enquires going up, the centre is falling short of space.



- 6. **Behavior Sheets:** The most important part is to draw behavior pattern of AD patients for which separate log sheets are prepared.
- 7. **Introduction of New Activities:** Since no two **PwDs** are the same as such activities for each differ and needs regular revision from time to time. Hence adding new activities is a regular feature in the facility.
- 8. **Documenting the Daily Patient Profile:** The most important part of A.S.H.A is to keep an hourly tab on the routine of the patients which also help us to keep a check on the working of caregivers.
- **9. Weekly caregivers training:** Every Friday, regular meetings for caregivers are conducted to understand their problems and concerns so that quick solutions are derived for better function of the facility.





In order to carry out all the above we have developed various formats through which proper monitoring and evaluation is done for our day care / residents **PwDs** and their caregivers

IMPORTAINT LINKS OF THE FACILITY

The under mentioned Project Related Videos Link gives an idea of our Day Care & Residential facility.

- 1. <u>https://youtu.be/hlgUzB0Tlb4</u> Inauguration Day of A.S.H.A. dated 11.08.2019
- 2. <u>https://youtu.be/zbb3i7TfYis</u> Day Care Activities by Alzheimer Disease Patients
- 3. <u>https://youtu.be/dK6C97gqlyl</u> Laughter Therapy at Day Care Centre A.S.H.A.
- 4. <u>https://youtu.be/O3ah3cANNds</u> Seating Exercises at Day Care Centre A.S.H.A.
- 6. <u>https://youtu.be/tTpqpUQ2swQ</u> Casio Activity at Day Care Centre A.S.H.A.
- 7. <u>https://youtu.be/jGF5YDxrHfc</u> Taking Out Alzheimer's Patients in nearby Park

IMPACT ASSESSMENT OF PwD BY PSYCHOLOGIST

Case Study - 1

Name - Dr. Baljeet Kaur, an 83 years old lady retired as a Doctor - CMO from CGHS -New Delhi.

Date of Addmission - Diagnosed with Alzheimer's in March 2019, was admitted at ASHA on 12th Dec 2019



PHOTOGRAPHS OF PwD

BEFORE



AFTER



Relatives

Son : Mr. Gurinder Jeet Singh Saini

Daughter : Mrs. Arvinder Duggal

Basic Concerns

- B. P. Patient
- Can't walk, uses a wheel chair
- Total duration of illness 1 1/2 years
- No teeth (No dentures)
- Incontinence (On diapers)

Chief Issues

- Forgetfulness (short term memory affected)
- Easy irritability and aggression
- Not able to take care of herself (totally dependent) (Now able to eat her meals of her own after being cared at ASHA)
- She doesn't have teeth and no dentures being used so eats food in semi- solid form

From December 2019 her son decided to shift her to residential care as he had to go abroad and there was no one to take care of his mother.

Psychological Examination

Neurological assessment was done by Dr. Priya Jha at the time of joining and thereafter.

General Appearance and Behaviour

- She is alert, tidy
- She is on wheelchair
- Eye contact is active
- Very dominating attitude
- Religious minded
- Not a fussy eater
- Speech and language relevant but firm



- Disturbance in comprehension
- Mostly affectionate and decent
- Recent memory impaired

Intelligence Level

- Above average and is proud of being a doctor.
- Abstract intelligence impaired.
- General knowledge satisfactory.(responds well to questions)

Diagnosis

Fronto – Temporal Dementia

Progress at ASHA

- Mrs. Baljeet Kaur is now more alert and more active
- Her appetite has improved and she eats well. Demands food of her own choice.
- Likes different Punjabi dishes which are specially prepared for her as per her demand.
- During the day she actively participates in activities like colouring, playing keyboard, simple craftwork and white board games. She gives intelligent answers to the questions asked.
- Her muscle power has improved physiotherapy being done at ASHA regularly.
- Is irritable sometimes but happy most of the time. Gives blessings to all care givers around.
- She loves music and Gurubani that is played in her room every morning.
- Has started reading her religious book sitting on a chair.
- She reads Hindi newspaper and likes to discuss about an issue with someone around.
- She has become more expressive.
- Positive changes observed in her cognitive and motor skills.



Case Study - 2

Name - Mr. J. P. Mittal, 93 years old male, retired Scientist from Government.

Date of Admission - Joined Day Care in August 2019. Shifted to Residential Care in September 2019

<image>

PHOTOGRAPHS OF PwD

BEFORE

AFTER

Relatives

- Wife Smt. Padma Mittal is a dementia patient, admitted in ASHA
- Son Mr. Vivek Mittal Buisness man.
- Daughter-in-law Mrs. Shalini Mittal House wife
- Daughter Mrs. Madhavi Mittal House Wife

Diagnosis

• Frontal Temporal Dementia

Basic Concerns

- Walks with a stick Severe Osteoporosis in both knees.
- Incontinence (on diapers)
- Has a chronic skin problem (on legs)



Chief Issues

- Forgetfulness (short term memory affected).
- Easy irritability and aggression.
- Partially dependent (needs help in ADL's like bathing, shaving, medication and little support while walking with stick).
- Disturbed sleep at times.

General Appearance and Behaviour

- He is alert and prefers to remain tidy.
- Walks with stick and little support.
- Eye contact is good.
- Affectionate but gets furious many times on issues related to food at times when he forgets he had his meals. He demands more food at that time. Rest he is decent.
- He is a fussy eater.
- Speech and language clear.
- Recent memory grossly impaired.
- Loves colouring. He is very good at selection of colours.

Psychological Examination

• Neurological assessment was done by Dr. Priya Jha, Chief Physiologist in August 2019 and September 2019 at the time of joining.

Intelligence Level

- Above average
- General knowledge satisfactory.
- Abstract intelligence impaired.
- Responds well to questions and adds his knowledge to the related topic.
- Very organised in doing any activity.
- Very good at mathematical calculations sometimes.
- Very good at solving toy puzzles.

Progress at A.S.H.A.

- Lot of changes observed in cognition and behaviour:
- He remembers the names of the care-giver attending to him and his wife.
- He does very good colouring and selection of colours is perfect till today.



- He enjoys craft work.
- He is very expressive in discussions amongst peers.
- He loves reading and listening to Hindi stories and is very good at comprehension part.
- He enjoys reading Hindi newspaper.
- Likes to have food of his choice and keeps instructing the cook giving him his cooking tips and new recipes.
- Likes to play keyboard (Casio).
- A lot of improvement observed in maths activities. Enjoys doing addition and subtraction.
- Urinary incontinence persists.
- Some changes observed recently in sleep patterns due to his cough and cold issues. Otherwise he sleeps well.
- Skin problem persists as it is chronic (Regular massage is done on affected areas to give him relief). No itching is there.
- He is demanding by nature. Criticism and appreciation go hand in hand in his case.
- His condition is not deteriorating. He is still active and alert even after 2 episodes of hospitalisation.
- Improvement observed in his motor skills.

Case Study - 3

Name - Ms. Mohuya Chaudhuri , 53 years oldWorked as Senior Editor, NDTV

Date of Admission - Diagnosed with Alzheimer's in September 2017, was admitted on 18.02.2020







BEFORE

AFTER



Relatives

- Husband Mr. R. Ramachandran
- Daughter Miss. Aparajita Chaudhuri

Basic Concern

- Incontinence (on diapers)
- Total duration of illness 3 years
- Has lost basic vocabulary
- BP (on medication)

Chief Issues

- Forgetfulness (short term memory affected)
- Not able to take care of herself (totally dependent)
- (Cannot express her needs due to loss of vocabulary)
- Over energetic and restless (doesn't sit at a place for long)
- From Feb 2020, her husband decided to shift her to residential care as managing her at home was becoming difficult for the family. Her husband was not able to concentrate on his work.

Psychological Examination

• Neurological assessment was done by Dr. Priya Jha at the time of joining and thereafter.

General Appearance

- She is tidy / energetic / restless
- Doesn't make eye contact
- Not a fussy eater
- Doesn't speak like a normal person, repeats a few words
- Disturbance in comprehension
- Recent memory impaired
- Recognition is very poor

Intelligence Level

- Has forgotten everything
- Abstract intelligence impaired
- Only remembers few lines of Hindi songs



Diagnosis

• Fronto Temporal Degeneration (FTD)

Progress at ASHA

- Her appetite has improved and eats well.
- Has started participating in daily activities looking at other patients.
- Many words have been added to her vocabulary with constant repetition by caregivers.
- Has started following instructions which was nil when she joined.
- Lot of improvement in her facial expressions and looks has been observed.
- She has started taking interest in selection of her clothes daily. Dress sense improved.
- Is less restless now and sits at a place quietly while doing puzzles and blocks.
- Recites Gayatri Mantra with caregivers.
- She has become more expressive.
- Has started doing colouring and craft work.
- Positive changes (though slow) observed in her sensory and motor skills.
- Behaves very nicely withcaregivers and shows signs of gratitude many a times.
- Is ever smiling now.

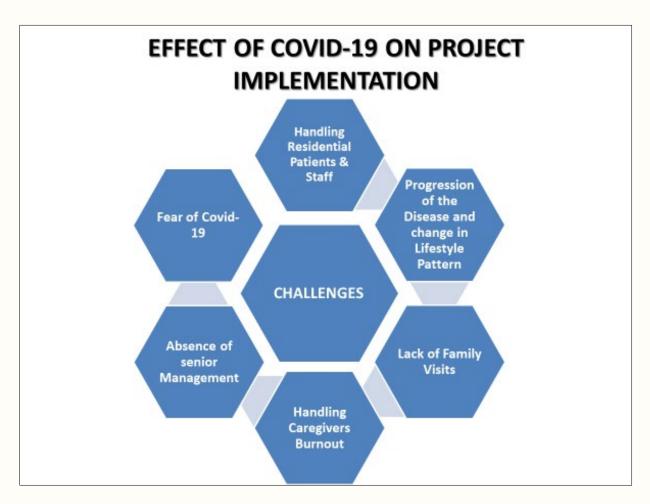
A.S.H.A. DURING COVID-19

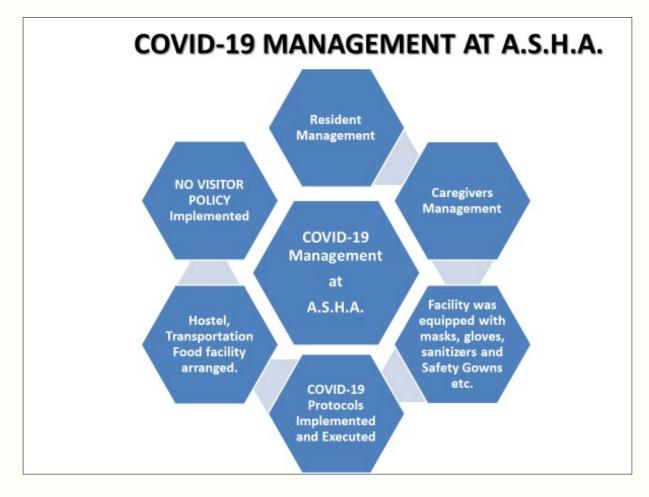
Whole world was hit by the most devastating pandemic of this century, leaving no sections untouched by its impact. The Covid-19 came as a challenge in front of every section of this society.

We as an organization deal with the most fragile community of this country, Elders and on top of it elders / **PwD**. So, dealing with them and keeping them safe was the biggest challenge in this pandemic

In the wake of COVID-19 pandemic, understanding the fragility of the patients ASHA took a complete patient centric approach to ensure that the patients at ASHA remain safe, secure & healthy.











INTRODUCTION OF ONLINE HOME CARE MODEL FOR OUR DAY CARE PwD UNDER THE PROGRAMME "Hope At Home"

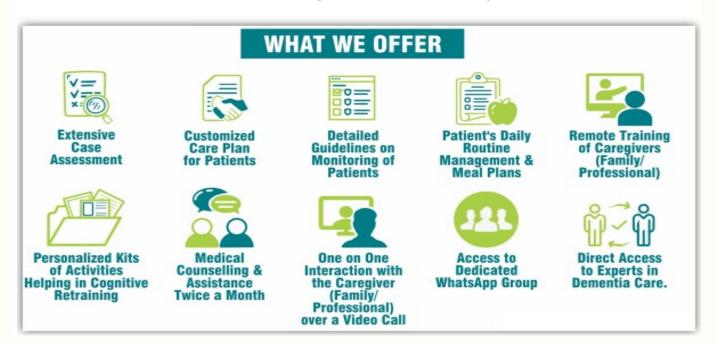
With the onslaught of COVID-19 pandemic, when world was trying to adjust to the new normal and in a bid to expand its services for people who are taking care of their loved ones, suffering from Dementia at home which is the most challenging task in these times, Hope Ek ASHA came up with a new initiative "Hope At Home" to provide dementia care and counselling services in the comfort of their homes.

"Hope at Home", the brainchild of Hope Ek ASHA, a home care plan that provides a structured program for **PwD** under regular guidance and supervision of trained and experienced professionals via virtual connect or over video calls. Family caregivers/professional caregivers are periodically counseled, prepared and equipped to take up the task of effective caring.

Since no two **PwDs** are same in their behavioral manifestations hence the approach to deal with them needs to be patient-centered. Thus, a customized care plan is developed and curated for each patient looking at his / her needs. In this model, family support is paramount.

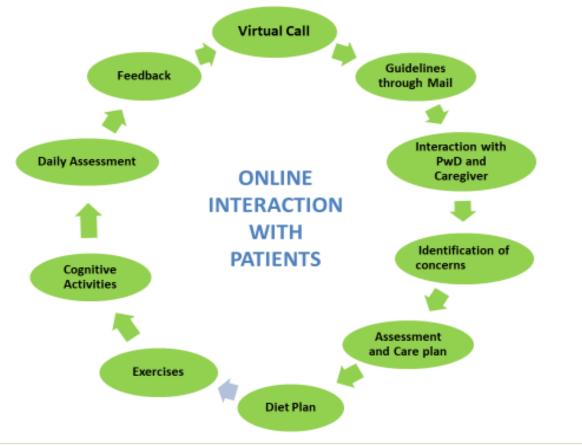


"Hope At Home" Programme for Day Care PwD



Please visit our Facebook page https://www.facebook.com/hopeekashango

Method of Monitoring and Evaluation of "Hope At Home"





Monitoring Tools of "Hope At Home" Program

> /	Application form
≻ ۱	_ife history form
> (Guidelines
≻ ⊧	Kit contents
> 1	Monthly calls roaster
۲ ۲	Time table
> 1	Nursing notes
ך (Daily Assessment
ا ≺	mplementation of Home care model

A Glimpse of "Hope At Home" for PwD





Case Study of PwD under "Hope At Home"

Name - Mr. Swapan Paul Age : 69 years.

Diagnosed with Alzheimer's in 2018

Joined "Hope At Home" dated :16.06.2020





Relatives

- Mrs. Aparna Paul, Wife
- Mr. Jimmy Paul, Son
- Miss. Pallabi, Daughter
- Miss. Shennaya, Grand daughter

Basic Concerns

- Short term memory affected
- Aggressive behaviour
- Mood swings.
- Fast reflexes posing danger of fall. No physical activities.
- Slept the whole day. Not interested in activities.

Chief Issues

- Forgetfulness (short term memory affected)
- Adamant at times while following instructions.
- Ate specific kind of food (Nutrients were missing)



- Physically abusive to members of the family when annoyed. Family had to use force to stop him.
- His past memories were not very pleasant which have converted into hallucinations now. Due to the above reasons, the family opted for Home care during Covid period.

Psychological Examination

• Neurological assessment was done by Dr. Priya Jha at the time of joining and thereafter .

Diagnosis

• Fronto temporal Dementia

General Appearance

- He is healthy looking / Energetic / tidy
- Fussy eater.
- Makes eye contact.
- Speaks less.
- Recognition poor.
- Recent memory impaired.
- Sleeps well.

Intelligence Level

- Recognises only daughter.
- Abstract intelligence partially impaired.
- Only speaks and understands Bengali language.
- Good at Maths.
- Can perform (ADL's)

Progress noticed

- Aggression in his behaviour has shown remarkable positive changes. He is calm most of the time.
- Has started participating in daily activities taught by the team.
- Recognition improved Has started recognising all family members with name impulse therapy.
- Has started following instructions.



- Facial expression has changed. He welcomes everyone with a smile.
- He is less restless now and enjoys reminiscence activities like folding laundry, sorting clothes of each family member, drying clothes etc.
- He has become more expressive and tells what he wants.
- He has started showing interest in watching T.V which he never liked. He is interested in watching cartoons and animals on TV and expresses his interests.
- His dietary habits have improved and nutrients have been added in his diet.
- Expresses kind attitude towards helpers at home and instructs his wife to give them money and food.
- Daily physical activities taught by our team have shown a lot of improvement in his postures, moods and appetite.



Executive Body 2019-20

S. No	Name of Member	Qualification	Profession & Address	Designation
1.	Dr. Sushma Chawla	M.B.B.S.	Doctor Professional, D - 52, G. K. Enclave - II, New Delhi -110048.	President
2.	Sh. Chaman Lal Narula	Graduate	Retired AGM United India Insurance Co., 87A, DDA Flats, Masjid Moth, Phase - II, New Delhi - 110048.	Vice President
3.	Sh. Harish Chandra Chawla	M.E. B.E. MSW (Pursuing)	Former Chairman Consumer Grievance Redressal Forum, Pushp Vihar, New Delhi – 110017.	Secretary General
4.	Sh. Talwant Singh	B.A., L.L.B	Judge (Delhi High Court) Sessions House, 2, Northend Road, Civil Lines, Delhi – 110054	Legal Advisor (Honorary)
5.	Mrs. Rita Sehgal	Post Graduate in Psychology	Social Worker, A – 5 / B – 198, SFS DDA Flats, Gate No. 6, Shanti Kunj, Paschim Vihar, New Delhi – 110063.	Joint Secretary & Editor
6.	Mrs. Sarla Kohli	M.A. (Economics)	Retired Manager, IDBI Bank, G - 35, Masjid Moth, New Delhi – 110048.	Treasurer
7.	Shri Sunil Pahwa	Graduate	Business (Opticians), 3C / 26, New Rohtak Road, New Delhi – 110005.	Executive Member
8.	Shri S. C. Kalra	Graduate	Govt. Officer, Retired B – 191, Lok Vihar, Pitam Pura, New Delhi – 110034.	Executive Member
9.	Mrs. Benu Bhargava	M.Ed., B.Ed.	Retired School Teacher E 366 Greater Kailash - II, New Delhi – 110048	Joint Editor
10.	Mrs. Charanjeet Kaur	B.A. (Final)	House Wife Sessions House, 2, Northend Road, Civil Lines, Delhi – 110054	Event Coordinator
11.	Shri Arun Kumar Trehan	Post Graduate	Business Zinat Mahal, Lal Kuan Bazar, Delhi – 110006	Benefactor



MAJOR CONTRIBUTORS DURING 2019-20













EVENTS DURING 2019-20

VISIT OF PRESIDENT Hope EK A.S.H.A. IN U.N. HIGH LEVEL CONFERENCE AT NEW YORK, USA

Dr. Sushma Chawla, attended United Nations High-Level meeting on Universal Health Coverage at United Nations Headquarters, New York, USA on dated 27.04.2019.

It was a widely attended meeting with delegates from all countries and regions. There were only two delegates from India. One from the Northern and other from Southern region of India.

The theme was the healthcare system and policies drafted by UNO in consultation with other countries and their health care systems. Discussions held with delegations from all countries.

The main focus was that NGOs should go back to their own country and sensitise the government to draft and implement Health Coverage policies in their respective countries to have a better world.





CORE GROUP MEETING ON UPCOMMING PROJECT AFFECTIONATE SECURED HOME FOR ALZHEIMER'S

Core group meeting was called on 25th of May 2019 at 4:00 pm. It was attended by 18 members.

Dr. Sushma Chawla stated formally announced the project A.S.H.A. (Affectionate Secured Home for Alzheimer)

She gave a brief background of the project and thanks the major sponsors of the project. She emphasized that the journey now has been possible with the support of all the members present and will be taking shape with the joint effort of whole team.

Member discussed the areas to be emphasized for the project.

The main areas were launching of a new dynamic website, registering volunteers, fund raising and plans to make the project self sustainable .

Meeting ended with a cup of tea and snakes.



AWARENESS TALK ON ALZHEIMER'S AT LADIES CLUB IN NOIDA

As a part of our activities, conducted an Awareness talk at Ladies Club, Sector - 14, NOIDA on 22.07.2019 at their request which was attended by 48 ladies in 50+ age group. Details about the project A.S.H.A. Affectionate Secured Home for Alzheimer were also discussed. https://www.facebook.com/hope.ekasha/posts/2020569634716202





VISIT TO LEBENSSHILFE SCHOOL AT VISHAKAPATNAM, A.P.

This visit was sponsored by one of our major supporter Shri Emandi Shankara Rao, CEO & MD of Industrial Financial Corporation of India Limited and IFCI Social Foundation for the benefit of special school children at Lebenshilfe Special School meant for the Intellectually Disabled, Sector 9, MVP Colony, Visakhapatnam, Andhra Pradesh - 530017

This school has 350 intellectually impaired children (100 residential) from the poorest segments of society are becoming happy, independent adults through a unique synthesis of special education methods from around the world, specialized training in local folk arts and a distinctive program using the arts as therapy.

It was founded in 1958 by Tom Mutters in Germany. After studying Special Education in America, Lebenshilfe India founder late Dr. Saraswathi Devi Tallapragada (Sarah) took intensive training at Lebenshilfe Germany. On her return to India, with support of the original organization, Sarah founded Lebenshilfe school in 1980.



Dr. Sushma Chawla, Mrs Rita Sehgal and along with two other members of NGO visited the school. Children were introduced Brain stimulating activities in the presence of their teachers. A full day workshops was organised on various motor and sensory activities. Teachers were also trained so that they repeat similar exercises and share in the classes. All these activities were taken from Delhi and were donated to school at the end the workshop. The volunteers took keen interest to learn all these activities and involved all the children.

At the end all teachers, training aid staff of school gathered with all mentally challenged children present in school and those who stay in the hostel premises to convey our thanks. They practiced arithmetic, Tiger Dance, played tabla and shown meticulously painting done by children.

It was a very fruitful and a learning experience for the children as stated by Principal of school. Visit was a great success.







MASS AWARENESS TALK ON "DEMENTIA" IN SENIOR CITIZEN FORUM OF NILGIRI APARTMENTS AT NEW DELHI

A Mass Awareness talk at Nilgiri Apartment, Alakhnanada in Senior Citizens Forum was conducted on 22.09.2019.

It was attended by more than 55 Senior Citizens. A talk on "Dementia" was given by the president and thereafter queries from Senior citizens present were answered by her and by our team members. The forum has also requested for a Memory Screening Camp in their colony for which separate date will be fixed. Programme Video link is <u>https://youtu.be/aPCM9526cyl</u>







WORLD ALZHEIMER'S DAY" AT INDIA HABITAT CENTRE, DELHI

Hope Ek A.S.H.A. celebrated "World Alzheimer's Day" on 28.09.2019 at India Habitat Centre, Delhi at a large scale as one of our activity of "Mass Awareness" which was dedicated to the Caregivers **"HEROS OF HOPES"**.

The distinguished speakers were Dr. K. S. Anand, Professor & Head, Department of Neurology, Ram Manohar Lohia Hospital, New Delhi, Dr. Sushma Chawla, President Hope Ek A.S.H.A., Dr. Jitendra Nagpal, Senior Consultant Psychiatrist, Moolchand Medicity Hospital and Ms. Neha Sinha, CEO & Co-Founder, Epoch Elder Care.

The event was attended by +100 delegates which included eminent doctors, caregivers, volunteers and representative of NGO.

• **Dr. Sushma Chawla** narrated the Hope Ek A.S.H.A. Journey and Building a Dementia friendly society.

• **Dr. K. S. Anand** from RML Hospital, delivered a lecture on "Old Age or Dementia?" and Boosting myths about Dementia.

- **Dr. Jitendra Nagpal** from Moolchand delivered a lecture on "Inside the Mind of a caregiver and De-stressing Techniques"
- Ms. Neha Sinha from Epoch Elder Care explained on "Caregiving" It's all about Perseverance & patients.

Video on tour of ASHA was played before the audience. And thereafter Question & answer session was extremely interactive.

The Chief Guest was Shri R. S. Dhillon, Director Chairman Power Finance Corporation Limited.

The Guest of Honours and our supporters were Shri K. D. Pandey, M.D. Geekeen Seating Collection and S.C. Kalra, Caregiver

Shri Dhillon appreciated the working of the society and promised to extend the help in the near future under CSR.

Vote of thanks was extended to all dignitaries and all present in the event by Shri C. L. Narula, Vice President, Hope Ek A.S.H.A.

The programme ended with National Anthem followed by lunch.







MASS AWARENESS TALK AMONG ALUMINI OF THAPAR COLLAGE

A "Mass Awareness Program" was organized on towards the **"Myths attached to Old Age"** and healthy life style tips were shared to Alumni of Thapar Collage on dated 13.10.2019, at E - 18A, East of Kailash, New Delhi - 110065.

It was a very interactive session as per the need of Elders. Tea and Snacks were served after the event.





MASS AWARENESS PROGRAMS ON HANDLING PWD AMONG THE STUDENTS OF "UNIVERSITY CONNECTION"

A "Mass Awareness Program" was organized on Alzheimer's / Dementia / Memory Loss for students of University Connection on dated 19.10.2019 at Facility.

It was a very informative session for students / young professionals to make them aware method to deal with PwD.

Two students had Dementia patients at their home and they were the caregivers for them. Tea and Snacks were served after the event.



MASS AWARENESS TALK AMONG CHARTERED ACCOUNTANTS

A talk on "How to enhance your memory" and healthy life style living was organised in a group of Chartered Accountants (CA's) on dated 20.10.2019 at D – 52, Greater Kailash, New Delhi – 110048. 15 CA's partipitated in the session. It was a very interactive session.







VISIT OF MEMBER OF NATIONAL HUMAN RIGHT COMMISSION (NHRC) AT THE FACILITY

National Human Right Commission (NHRC) team, headed by Dr. D. M. Mulay, Member NHRC, Visited A.S.H.A. "Affectionate Secured Home for Alzheimer's" on 06.11.2019 at 04:00 PM and he was briefed about the Residential and Day Care Facilities available for Senior Citizens suffering from Alzheimer's Disease (PwD).

He was asked to get us a land from the Govt. for opening an Alzheimer's Home. He promised that he will take up the matter at Ministerial Level. Meeting ended with light refreshment.



LECTURES ON ALZHEIMER'S / DEMENTIA (MEMORY LOSS)

A get together was organised by CA Raj Chawla on 22nd Dec 2019 (Sunday) at Free Massion Club, Connaught Place, Janpath, New Delhi - 110001



Dr. Sushma Chawla, President Hope Ek A.S.H.A. gave a short lecture on Alzheimer's disease / Dementia (Memory Loss). After the lecture she introduced our pilot project of Alzheimer's Home (A Residential & Day Care Skilled Nursing Centre) for PwD in South Delhi.

It was attended by 16 people. Books of FAQs on Alzheimer's disease were given to all of them.



SHARE & CARE MEET OF FAMILY CAREGIVERS

This concept SHARE & CARE was initiated by Dr. Sushma Chawla President on dated 04.01.2020. The session started on a cup of coffee. The focus was on the present family caregivers who are caring for their beloved ones at home. Five caregivers attended the meet, the names are as under.

Caregiver's Name

- 1. Ms. Seema Mishra
- 2. Dr. Daljeet Uppal
- 3. Col. Atul Madan
- 4. Ms. Jyotsna & Husband
- 5. Dr. Shalini

Remarks

- Her Mother is suffering from Alzheimer's
- Her Husband is suffering from Alzheimer's
- His wife is suffering from Alzheimer's
- Her Mother is suffering from Alzheimer's
- Her Father is suffering from Alzheimer's



Caregivers shared their problems and techniques how best they are dealing with them. Professional advice was given by Dr. Sushma Chawla and Dr. Priya Jha, Chief Psychologist.

The time for the meeting was scheduled as 1 hour but lasted for 2 hours.

Importance of Yoga and Exercise was discussed by Ms. Rubina Hasan (Volunteer). It was a good session and all gave their concurrence to conduct such session from time to time. The next session is likely to be announced in April 2020.



AWARENESS TALK ON ALZHEIMER'S / DEMENTIA (MEMORY LOSS)

An Awareness Talk conducted on Alzheimer's / Dementia and Memory Enhancement tips among the Judges and Advocates at Session House, New Delhi on dated 19.01.2020 - beginning of winter. Book FAQs on Alzheimer's disease was distributed to all of them. The meeting was attended by 15 Judges and Advocates.





Hope Ek A.S.H.A. Annual Report 2019-20



B-NEUROFIT PROGRAMME FOR PwD

Dementia is an umbrella term for several neurodegenerative disorders which impact one's cognitive skills including memory, communication, attention, thinking, motor skills and behaviour. Neuro Degeneration basically means that the neurons in the brain are progressively deteriorating due to various risk factors like age, sedentary lifestyle, stroke, depression, trauma, lack of cognitive, physical and social stimulation.

An eight days programme called B-Neurofit was conducted by a clinical psychologist Ms. Banika Ahuja for the day care and residential care PwDs started on 22.01.2020.





MASS AWARENESS TALK DR. HANSRAJ VIRMANI HALL, DSCW, BLOCK - C, NEW FRIENDS COLONY, NEW DELHI

A "Mass Awareness Program" for Senior Citizens on Dementia / Alzheimer's disease was organized, on dated 31.01.2020, at Dr. Hansraj Virmani Hall, Delhi State Counsel of Women, Block C, New Friends Colony, New Delhi - 110025

It was a very interactive session and was attended by 18 ladies.



MASS AWARENESS FOR SENIOR CITIZENS ON DEMENTIA ATARYA SAMAJ MANDIR, LAJPAT NAGAR, NEW DELHI

A Mass Awareness Programme for Senior Citizens on Dementia / Alzheimer's Disease was organized on dated 08.03.2020 at C-Block, Arya Samaj Mandir, Lajpat Nagar, New Delhi - 110024.

Nearly 35 male & female including senior citizens participated in the event. The event continued for three hours in the forenoon. It was an interactive seminar to aware the senior citizens about dementia. It was very well explained that how dementia patients should be taken care at home when signs of dementia appears in them i.e. when they start forgetting in the beginning.

It was offered by our NGO to the administration of Arya Samaj Mandir that day care Activities / workshops can be arranged in this premises and some volunteer can be trained to continue in future. Tea and snacks were served after the event.





CARDIOPULMONARY RESUSCITATION (CPR) TRAINING FOR CAREGIVERS AT THE CENTRE A.S.H.A.

CPR (Cardiopulmonary Resuscitation) training was conducted on dated 13.03.2020. It is the most important skill that must be known to everyone in this fast moving world so that one can help to someone in saving his / her life during emergency.

A CPR training session was conducted by Dr. Sushma Chawla, President and visiting doctor J. Kailash for all the caregivers, nurses and the non technical staff of A.S.H.A. The session continued for one hour.









Hope Ek A.S.H.A - TOUCHING LIVES

"I am very pleased that I chose Hope Ek ASHA for my mother Kusum Sharma who is a neuro patient age 73years. She was diagnosed with first stage dementia and was in depression for some time. Their commitment to client care and integrity of their staff make families of loved ones completely at ease knowing that they are being looked after the way a family member would look after them.

In essence, I am happy to say that Hope Ek Asha is our "extended family." I would highly recommend them to anyone who asks for daycare as well as in house care as they are, in my opinion, the best and most trusted in their field. My best wishes for this amazing venture by Hope Ek Asha.

Dr. Shivani Khetan, Ph.D. DSc, Alternative Healing Medicine

"A.S.H.A. is based on my personal experience in engaging with the organization, the care home in particular, which has been the new home for my wife,, a former TV journalist with the NDTV. I am particularly happy about the compassion, friendliness, personal attention and medical care that my wife receives there and greatly appreciate the sincerity and dedication of all the attendants and the staff of the place. As a result of the efforts put in by the people at the centre, my wife has shown distinct improvement in some of her cognitive abilities, nearly all of which she had lost as a result of the disorder. I am indeed glad that the centre has enabled this perceptible improvement in her. I wish A.S.H.A. every success in their noble endeavours."

-R. Ramachandran, Science journalist

"My mother Dr Baljeet Kaur Saini, a dementia patient has been in house patient with Hope Ek Asha. It is a home away from home with dedicated staff to take care of in-house patient. In addition to normal care, the Centre makes consistent effort to ensure upkeep for cognitive faculties of the patient by having regular mental and physical exercises. This Centre is a blessing and a HOME away from home.

My special gratitude to Dr Sushma Chawla and the support staff of the Centre for this outstanding humanitarian effort despite all odds."

Brig. GJS Saini

"The society is indebted to you for the great work that you have been doing for the last 19 years."

Atul Madan



PROJECT PARTNER'S APPRECIATIONS

"We are really happy to have partnered with Hope Ek A.S.H.A in supporting the cause of Dementia care in India. Hope Ek ASHA is doing some incredible work in the field of Alzheimer's with an aim to build a dementia-friendly society. The Hans Foundation remains committed to bringing positive change in the lives of people through its farreaching community-centric activities."



Lt. Gen. S.M. Mehta (Retd.), AVSM, SM, VSM** Chief Executive Officer, The Hans Foundation.

"Myself along with IFCI Social Foundation team are humbly associated in Dr. Chawla's great initiative of setting up A.S.H.A. by providing a brief support in the medical equipment and other physical infrastructure. This state-of-the art medical facility is well utilized to treat patients with care. The facility acts as Skill Development centre to train the medical and caregiving staff in managing the patients



Dr. Emandi Sankara Rao MD & CEO - IFCI Limited and Chairman, IFCI Social Foundation